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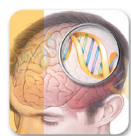
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Risk and protective factors for the health of primary care-givers of children with autism spectrum disorders or intellectual disability: a narrative review

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Abstract

Background: Primary care-givers of children with autism spectrum disorder (ASD) or intellectual disability (ID) have poorer health and quality of life than primary care-givers of typically developing children. We aimed to review original research which described factors impacting the health of primary care-givers of children with ASD or ID and to discuss how these factors might influence care-giver health.

Methods: We searched electronic databases and retrieved 33 relevant research articles.

Results: Factors impacting primary care-giver health included child behaviour, support and diagnostic issues. We explain how these factors might impact care-giver health and how they might act differentially in care-givers of children with different types of ASD or ID. Interventions to moderate one or more risk factors could pave the way for improved primary care-giver health.

Keywords: Autism, intellectual disability, mothers; care-givers, health, review

Introduction

A person with autism spectrum disorder (ASD) has a life-long neuro-developmental disability which is diagnosed by severe deficits in social communication and interaction, along with restricted or repetitive behaviour and interests [1]. Intellectual disability (ID) is diagnosed in persons with an IQ below 70 along with impairments in adaptive functioning both of which must be present before 18 years [1]. The prevalence of ASD varies between countries with a median of about 60 per 10,000 [2] while the prevalence of ID is higher at 104 per 10,000 [3].

There is a general consensus among researchers that *Quality of Life* (QoL) incorporates measures of physical functioning, mental health and engagement in social interaction [4]. A plethora of research has identified poorer health and QoL in the primary care-givers (here after referred to as care-givers) of children with ASD or ID than in other care-givers [5-11]. For example, using linked data, we demonstrated that in the years after their child's birth, mothers of children with ASD or ID had higher rates of psychiatric disorders than other mothers [9,10]. Furthermore, we also identified health differentials in mothers of

children with different sub-types of ASD or ID [12]. Using the *12 Item Short Form Health Survey* (SF-12), parents of children with ASD without ID were also reported as experiencing lower QoL and more stress than parents of children with ASD with ID [7]. Moreover, mothers of children with ASD had more self-reported anxiety and depression than mothers of children with Down syndrome [13]. Care-giver health issues challenge a family's QoL and may impact the care and healthy development of all children within the family [14,15]. Identifying risk factors for care-givers of children with a particular developmental disorder would enable the identification of groups whose health is especially vulnerable. In addition, identifying both risk and protective factors would enable a better understanding of the health trajectories of care-givers of children with ASD or ID. In such ways, informed interventions and services might be developed to assist in optimising care-giver health. Therefore, we aimed to review the research literature in the area of care-giver health, ASD and ID to locate original research which described risk and/or protective factors for health in care-givers of children with ASD or ID. Our second aim was to discuss how

these factors might influence care-giver health.

Methods of the review

We searched the electronic databases, *Web of Knowledge*, *Medline*, *Scopus* and *Google Scholar*, using combinations of the following groups of search terms associated with ASD and ID along with care-giver health. These included terms which are related to:

- ASD, ID or sub-groups such as *autism*, *autistic*, *pervasive development disorder*, *intellectual disability*, *mental retardation*, *disability*, *disabled*, *Down*, *Asperger*;
- Health such as *health*, *depression*, *physical*, *mental*, *psychiatric*, *psychological*, *phenotype*, *quality of life*, *well-being*;
- Care-givers such as *mothers*, *parents*, *care-givers*.

We included an original paper in our review if it:

- Was published between 1st January 1990 and 31st December, 2016
- Described original research in a peer-reviewed article which was written in English
- Used a study population of 15 persons or more
- Described a risk or protective factor for poorer health in mothers, parents or care-givers of a child with ASD or ID or a sub-type (such as ASD with ID or Down syndrome).

Using research [16,17], we developed a simple and objective five-level tool to assess the strength of evidence provided by the papers in this review (Table 1).

Results

We retained 33 articles. Table 2 summarizes each paper, provides an assessment of the quality of evidence, methods of data collection and recruitment, country of origin, study population, comparison group and the strength of the assessed relationship or a key result.

Discussion

In the first section, we discuss the papers retrieved for the review according to the reported risk or protective factors for poorer care-giver health or QoL. In the second section, we examine care-giver health disparities according to the child's diagnosis and the likely impact of particular risk or protective factors. The final section examines how risk and protective factors might impact the health of care-givers of children with ASD or ID.

Challenging child behavior

Challenging child behaviour, the most commonly identified risk factor for poorer care-giver health and QoL outcomes, was reported in ten of the 33 studies. Researchers provided substantial evidence that the social impact of the child's disability [18] and challenging behaviours [19-25] in children with ASD or ID was associated with poorer care-giver mental health. At the same level of evidence, challenging child behaviours in children with ID were related to poorer care-giver physical health in subsequent years [26]. The total score for the Jenkins Behaviour Questionnaire was higher in children with care-givers having two or more symptoms of depression ($p=0.004$) [27]. Symptoms of anxiety ($p=0.06$) and stress ($p=0.08$) were related also to challenging child behaviour though the associations did not reach statistical significance. These associations were predominantly due to issues of discipline (control, tantrums, demanding attention) and disturbances in sleep [27].

Challenging child behaviours had a negative effect on care-giver and family QoL. One research group administered the Parental-Developmental Disorders-Quality of Life Scale (Par-DD-QoL) to the parents of children with ASD and provided weak evidence that challenging child behaviour was an independent risk factor for poorer QoL [28]. Results from a qualitative study were similar [24].

Level of support

Support networks were associated with improved care-giver health and QoL in families of a child with ASD or ID. For example, substantial evidence indicated that family support reduced care-giver burden in families with a child with ASD [20,29] and that family and neighbourhood support was associated with improved parental mental health [20,30,31] and reduced parental aggravation or irritability [32]. Further substantial evidence [33] [as classified by our descriptors on Table 1] was provided using the *Multidimensional Scale of Perceived Social Support* (MSPSS) which indicated that greater social support was associated with lower levels of individual distress (apart from anxiety and depression) in the families of children with ASD [25]. Alternatively, substantial evidence demonstrated that mothers of children with ASD had poorer mental health than other mothers but no less social support for parenting [34].

Higher levels of support had a similar favourable effect

Table 1. Assessment of level of evidence

Level of evidence	Narrow descriptor	Broader descriptor	Description of study
5	Strong	Substantial	Validated scores & magnitude of effect assessed
4	Moderate		Validated scores but no magnitude of effect assessed
3	Mild		Magnitude of effect assessed but no validated scores
2	Weak	Less substantial	No validated scores or assessment of magnitude of effect
1	Indication only		Descriptive study

Table 2. Details of papers included in the review.

Study	Level	Outcome measurement*	Recruitment	Country of origin	Study population	Comparison groups	Variables investigated		Strength of relationship (1 vs 2) or key result(s)
1	2	3	4	5	6	7	1	2	9
1. Baghdadli, 2014 (28)	2	Parental-DD-QoL Scale	ASD evaluation clinics	France	152 mothers of children with ASD, 182 others	ASD, severe chronic diseases	Child behaviour (ABC)	Parental QoL	Child behaviour was an independent risk factor for parental QoL
2. Bourke, 2008 (19)	5	SF-12	Service providers	Australia	250 cases	DS, pop norm	Independence of learning skills (WeeFIM-m)	Maternal PH	Mothers of children with <i>independence of learning skills</i> had better PH than mothers of children without
							Child behaviour (DBC)	Maternal health	Negative association of PH & MH with poorer child behaviour (PCS: coefficient=-0.3, MCS: coefficient=-0.8)
3. Bromley, 2004 (20)	5	GHQ-12	Service providers	UK	68 mothers	ASD	<ul style="list-style-type: none"> Child behaviour (DBC) Family support (FSI) 	Maternal distress	Maternal distress was associated with poor child behaviour & lower family support
4. Caldwell, 2008 (37)	5	SF-36	Service providers	US	1,400 cases	DD, pop norm	Access to services (FSI modified)	Maternal PH	Negative association of PH with poorer access to services (coefficients=-0.2)
5. Cantwell, 2014 (38)	5	Physical Health Questionnaire	University/other	Ireland	109 cases	DD, TD	Support (SFS)	Maternal PH	No direct relationship between PH & support needs Effects of stress on PH moderated by social support
6. Corrice, 2009 (43)	4	Subjective Well-being, Child-Related Scale	Service providers & community	US	120 mothers	DS, DD not DS	Personal rewards (TDRWQ)	Maternal well-being	DS mothers had higher average reward & subjective well-being compared to mothers of children with other DDs.
7. Dardas, 2014 (41)	3	WHOQOL-BREF	Community	Jordan	184 parents	AD	Income	Parental QoL	Correlation=0.2 between parental income & QoL
8. De Grace, 2014 (46)	1	Interviews	Community	US	7 families	ASD	Family experiences	-	Not applicable
9. Eisenhower, 2013 (26)	5	Single-item measure for PH	Service providers	US	116 cases	TD, DD	Child behaviour (CBC)	Maternal PH	Poorer child behaviour was associated with poorer PH in DD group.
10. Emerson, 2003 (18)	5	GHQ-12	Survey participants	UK	245 case mothers, 9,481 control mothers	ID, No ID	Social impact of child's difficulties (SDQ)	Maternal MH	No direct relationship between the social impact of child's difficulties & MH
11. Emerson, 2010 (39)	3	Kessler-6	Previous study	UK	More than 15,000 parents	Cognitive delay	Severe delay, Less severe delay, TD (BBCS & NVS)	Maternal psychiatric disorder (MPD)	<ul style="list-style-type: none"> RR=1.5/1.2 for MPD & child with severe/less severe delay at 5 years compared to mothers of TD child Low SES associated with having MPD
12. Estes, 2009 (21)	4	Questionnaire assessing stress	Service providers	US	51 ASD, 22 DD no ASD	ASD, DD no ASD	Child behaviour (ABC)	Maternal stress	Mothers of children with ASD had higher average stress & children with ASD had poorer child behaviour.
13. Firth, 2013 (22)	4	PSS	Service providers & community	Australia	109 parents	ASD	Child behaviour (NCBRF)	Parental distress	Positive association of distress with poorer child behaviour (coefficient ≈ 0.3)
14. Harvey, 1997 (27)	4	Items from DSSI & GHQ-28	Service providers	Australia	65 cases	DD, TD	Child behaviour (Behaviour Checklist of Jenkins)	Maternal depression	No association of depression with child behaviour
15. Herring, 2006 (23)	4	GHQ-28	Child clinic	Australia	123 parents	PDD, DD~PDD	Child behaviour (DBC-P)	Parental MH	Poorer maternal MH was associated with poorer child behaviour (regression coefficient ≈ 10.11).
16. Hoppes, 1990 (42)	3	Ad hoc questionnaire	Service providers	US	38 mothers	ASD, DS	Child's disability group	Maternal gratification (ad hoc questionnaire)	<ul style="list-style-type: none"> Mothers from ASD group had less gratification than DS mothers Improved MH with more support
17. Ingersoll, 2011 (52)	3	CES-D	ASD web site	US	90 case mothers	ASD	BAO, ASQ Autism severity (Autism Behavior Checklist)	Maternal depressed mood	Increased depression attributed to both stress of child & BAP.
18. Ingersoll, 2011 (30)	4	CES-D	ASD web-site	US	149 parents	ASD	Social support (MOS-SSS)	Parental depression	Correlation ≈ -0.5 between social support & parental depression
19. Ji, 2014 (29)	4	SF-36	Service providers	China	273 care-givers	ASD	Carer load (Care-giver Burden Index)	Care-giver health	Negative association of increased burden of care & care-giver health (PCS: coefficient=-0.4, MCS: coefficient=-0.59).
							Social support (MSPSS)	Care-giver health	Positive association of care-giver health with increased social support (PCS: coefficient=0.25, MCS: coefficient=-0.24).
20. Kelso, 2005 (45)	1	Interviews	Schools, support groups	Australia	26 carers of children with disability	Not applicable	-	-	-
21. Lach, 2009 (63)	5	Short version of CESD	Previous study	Canada	9,467 carers	Carers of child with neuro dis & behaviour problems, Carers of children w/out	Disability group (Health Utilities Index)	Carer depression	Increased depression in carers of children with neurological disorders.
22. Lenhard, 2005 (47)	3	<ul style="list-style-type: none"> Ad hoc questionnaire S-T-A-I 	Service providers	Germany	411 DS, 66 ID of unknown cause & 69 TD mothers	Mothers of children with DS, ID of unknown cause, TD	Disability group	Maternal anxiety	Mothers with no diagnosis had higher levels of anxiety than DS mothers who had higher levels of anxiety than mothers of TD children.
23. Lingen, 2015 (48)	5	Ulm Quality of Life Inventory for Parents	Parents of patients with DD/ID at University Hospital	Denmark	95 mothers	Mothers of children with diagnoses, mothers of children without	Etiological versus no etiological diagnosis for DD/ID after genetic testing (aCGH)	Maternal QoL	Maternal QoL score was 20.2 percentile rank scales higher in mothers of children with diagnoses compared to mothers of children with no diagnoses.

Continuation of Table 2.

Study	Level	Outcome measurement*	Recruitment	Country of origin	Study population	Comparison groups	Variables investigated		Strength of relationship (1 vs 2) or key result(s)
24. Llewellyn, 2010 (35)	5	SF-12	Service providers	Australia	64 older parent carers (>60 years)	Parents of children with ID vs pop norm	Age group	Care-giver MH	Amongst carers over 54 years, mental health improved with age.
							Partner	Care-giver PH	Carers with partners had better PH.
25. McStay, 2014 (24)	4	PSI	Autism Centre	Australia	196 parents & population norms	Parents of children with ASD	Child behaviour (BASC-2)	Maternal & paternal stress	Better child behaviour & increasing marital support predicted reduced maternal stress
							Marital support (DAS)		
26. Montes, 2007 (34)	3	Maternal overall health measured by 1 question	Previous study	US	61,772 mothers	Mothers of children with ASD, TD	Disability group	Maternal MH	Having a child with ASD was associated with poorer MH.
27. Mugno, 2007 (33)	5	WHOQOL-BREF	Service providers	Italy	135 cases, 42 controls	Mothers of children with PDD, TD	Disability group (DSM4-TR)	QoL	Controls had better QoL than parents of children with PDD.
28. Olsson, 2001 (36)	5	BDI	<ul style="list-style-type: none"> Service providers (for cases) Randomised mailing (for controls) 	Sweden	216 case, 214 control mothers	Mothers of children with ID with/w/out ASD & controls	Disability group	Maternal depression	<ul style="list-style-type: none"> Mothers from ASD group had less gratification than DS mothers Improved MH with more support
29. Paynter, 2013 (25)	5	PSI-SF	Community	Australia	43 parents	ASD	Child behaviour (SDQ)	Parental stress	Positive association of stress & poorer child behaviour (coefficient=0.65)
							Support (MSPSS)	Parental stress	Negative association of support & stress (coefficient=-0.60)
30. Schieve, 2011 (32)	3	Aggravation in Parenting Scale (APS)	Previous study	US	872 cases	ASD, TD	ASD TD	Parental aggravation	Parenting a child with ASD was associated with more aggravation.
31. Singhi, 1990 (40)	3	SBS	Service providers	India	50 case parents	ID, TD	ID, TD (Used 1 or 2 of items below to assess IQ) GDT, SFB, MIS, VSMS	Social burden	ID parents had higher burden: ID=14.6, Control=0.72.
32. Werner, 2015 (44)	4	AFS	Convenience sample	Israel	171 care-givers	DD	ID, ASD, PD	Affiliate stigma	Stigma was highest in care-givers of children with ASD.
33. Zablotsky, 2013 (31)	3	1-item health index & 3-item stress index	Previous study	US	1,014 cases & 55,553 controls	ASD, no ASD	Stress (3-item index) Supports (5-item index)	MH	<ul style="list-style-type: none"> Mothers of children with ASD were more than 7 times more likely to have high levels of stress & nearly 3 times as likely to have poorer MH Increased support associated with better MH

ABC, Aberrant Behavior Checklist; AD, autistic disorder; AFS, Affiliate Stigma Scale; Array-based comparative genomic hybridization, aCGH; Autistic disorder; ASD, Autism spectrum disorder; ASD/ID, ASD or ID; ASQ, Autism Spectrum Quotient; BAP, Broad Autism Phenotype; BASC-2, Behaviour Assessment System for Children, Second Edition;BBCS, Bracken Basic Concept Scale; BDI, Beck Depression Inventory; carer, care-giver; CBC, Child Behaviour Checklist;CES-D, Center for Epidemiological Studies-Depression Scales; DAS, Dyadic Adjustment Scale; DBC, Developmental Behaviour Checklist;DBC-P, DBC-Primary Carer Version; DD, developmental disability, disorder or delay; dis, disability; DS, Down syndrome; DSSI, Delusions Symptoms States Inventory; ; FAD, MacMaster Family Activity Device; FQoL, Family QoL; FSI, Family Support Index; GDT, Gessel's Drawing Test; GFS, General Functioning Scale;GHQ-12, General Health Questionnaire-12-item version; GHQ-28, General Health Questionnaire-28-item version; HFASD, High-functioning ASD; ID, intellectual disability; Level, Level of evidence; MCS, Mental Component Summary of SF-36; MH, Mental health; MIS, Malin's Intelligence Scale; MSPSS, Multidimensional Scale of Perceived Social Support;MOS-SSS,Medical Outcome Study-Social Support Survey; NCBRF, Nisonger Child Behaviour Rating Form; neuro, neurological; NVS, Naming Vocabulary Subscale; PCS, Physical Component Summary of SF-36; PH, Physical health; pop, population; PSS, Parental Stress Scale; OR, odds ratio; PD, physical disabilities; PDD, Pervasive development disorder; PSI, Parenting Stress Index; PSI-SF, PSI: Short Form; QoL; Quality of Life; RR, risk ratio; SBS, Social Burden Scale; SDQ, Strengths and Difficulties Questionnaire 4–10 years: version for Australia; SF-12, 12-Item Short Form Health Survey; SF-36, 36-Item Short Form Health Survey;SFB, Seguin Form Board; SFS, Support Functions Scale; S-T-A-I, State-Trait-Anxiety-Inventory; German form; TD, typically developing; TDRWQ, Transition Daily Rewards and Worries Questionnaire; VSMS, Vineland Social Maturity Scale; WeeFIM-m, Functional Independence Measure for Children: modified; WHOQOL-BREF, World Health Organization Quality of Life-Brief.

on parents with a child with ID [31-34]. Using the SF-12, an Australian study [35] provided substantial evidence (as defined in Table 1) that better mental health in parents older than 60 years was associated with having a partner and a large and supportive network of family, friends and neighbours. Others [36] used the Beck Depression Inventory and reported that single mothers living with a child with ID were more depressed than similar mothers living with a partner. There is also substantial evidence that poorer physical health in female care-givers of adults with developmental disabilities was associated with a lack of services [37] and that the effect of stress on physical health was moderated by parental social support [38].

Socio-economic status

Higher socio-economic status (SES) was a protective factor for parental health and particularly maternal health [39-41]. For example, correlational analyses showed that parents of children with ASD with higher incomes had less distress and an improved QoL compared with those of lower incomes [41]. Similarly, there was strong evidence that socio-economically disadvantaged mothers had a greater risk of a psychiatric disorder than socio-economically advantaged mothers with a child with a similar disability [39,40].

Rewards and stigma

In a comparison of mothers of children with Down syndrome (n=21) and mothers of children with ASD (n=17), researchers provided some evidence of greater attachment and gratification in the mothers of children with Down syndrome [42]. A case-control study, with a lower evidence-base [43], reported that mothers of children with Down syndrome felt more rewarded by parenting than mothers of children with other developmental disabilities.

Affiliate stigma (or self-stigmatization) was higher among care-givers of persons with ASD compared to care-givers of persons with ID or physical disabilities although the level of evidence was not strong [44]. There was also evidence that there was additional societal stigma towards the care-givers of children who appear normal but manifest abnormal behaviours [45].

Diagnostic issues

Diagnostic uncertainty and an unclear prognosis are factors which can cause the greatest concern to care-givers of children with ASD and those for whom a cause of their child's ID has not been identified [45-47]. The first of these studies [45] used a combination of interviews or focus groups with care-givers and the second [46] provided qualitative evidence by interviewing care-givers. In the third [47], German researchers compared the mothers of children with Down syndrome, ID of unknown cause and typically developing children with respect to anxiety, guilt and emotional burden using the *State-Trait-Anxiety-Inventory* and the *Balanced Inventory of*

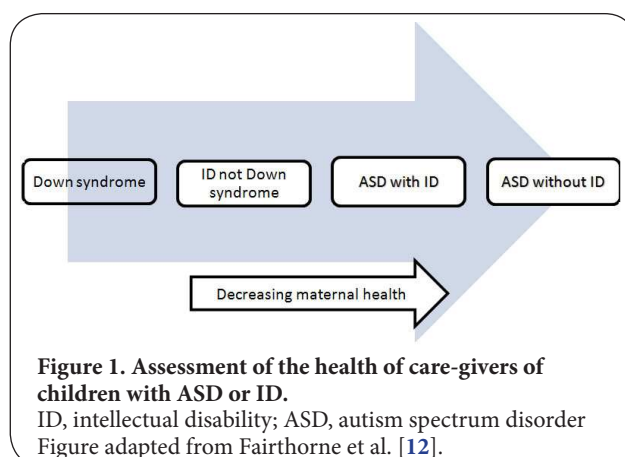
Desirable Responding. They concluded that uncertainty was a major cause of stress in mothers of children with ID of unknown cause [47]. A fourth study used the *Ulm Quality of Life Inventory for Parents* to examine the QoL of parents of a child with a developmental disability before genetic testing and after receiving a genetic cause for their child's disability. The results provided strong evidence that maternal QoL was improved once the underlying diagnosis was known [48].

Broad Autism Phenotype

The concept of mild autistic traits in the relatives of a person with ASD is termed the *Broad Autism Phenotype* [49]. Validated questionnaires such as the *Autism Spectrum Quotient* [50] and the *Broad Autism Phenotype Questionnaire* [51] are used to quantify the extent of this trait on a linear scale. Two research groups [30,52] provided mild and weak levels of evidence that persons exhibiting the Broad Autism Phenotype were at an increased risk of depression.

Maternal health by the child's diagnosis or sub-type and the impact of risk factors

In a previous review [12], we found that mothers of children with Down syndrome generally had better health than mothers of children with other intellectual disabilities. In turn, mothers of children with intellectual disabilities other than Down syndrome, generally had better health than mothers of children with ASD [especially ASD without ID] (Figure 1).



The disparities in the health of care-givers of children with ASD or ID may be partially explained by child characteristics associated with the particular diagnostic category. For example, challenging behaviours occur more often and are usually more severe in children with ASD than children with Down syndrome [53]. Thus, a commonly cited risk factor for poorer care-giver health and QoL outcomes, challenging child behaviour, is more often associated with ASD than Down syndrome. The increased likelihood of parents of children with ASD manifesting a *Broad Autism Phenotype* and its association with depression [30,52] could explain why poorer

mental health is more common in parents of children with ASD than in parents of children with other developmental disabilities. Furthermore, personality type influences a person's willingness to seek support [54]. Hence, the lower social support evidenced in families with a child with ASD could be mediated by parental personality traits which are associated with the Broad Autism Phenotype. The consequent overall reduction in social support could thereby further increase the risk of poorer mental health in these parents. Moreover, the lag-time to diagnosis in comparison to Down syndrome, where children are diagnosed at birth, could also impact negatively on the mental health of parents of children with ASD. Furthermore, mothers of children with Down syndrome mostly reported that parenting was more fulfilling than did mothers of children with other disorders [42]. In contrast, care-givers of children with ASD were the most negatively affected by stigma [44], a risk factor for care-giver health. Moreover, Down syndrome is the most common genetic form of ID and children are readily recognised and supported by members of the community due to their distinctive phenotype [55]. On the other hand, children with ASD have no distinguishing phenotype and mostly appear physically normal to community bystanders [56]. Thus, there is the expectation that their behaviour would be normal which may not be the case [45].

How risk and protective factors might impact care-giver health

We have identified a total of seven risk or protective factors for health and QoL in the care-givers of children with ASD or ID. The impact of challenging child behaviour seems likely to be mediated by the increased parental stress generated by antisocial, and the sometimes dangerous and self-limiting behaviours in the child [57]. Challenging antisocial child behaviours such as running away and self-injurious behaviour such as head-banging can also severely limit family activities and thereby increase family social isolation [58]. Additionally, antisocial behaviour, when unexpected by the outsider, could further exacerbate the stigmatisation of parents [59]. Increased levels of extended family support and other support given to parents and their family were positively associated with parental well-being [20,30,31]. Support provides relief for care-givers and in so doing provides opportunities for respite and thus engagement in social activities which might normally be reduced in care-givers of children with ASD or ID [54]. Socio-economic status may further impact on care-giver health since only well-resourced families may be able to gain support by enlisting paid care-givers and respite. Research has also found that families of lower SES have less knowledge of available support [60] and this may be because they are not equipped with the skills or assertiveness to navigate the systems.

Parents of children without a diagnosis for their disability can be disadvantaged [61] by the resultant lack of anticipatory and reproductive guidance, along with support by

networking with parents of children with a similar diagnosis. Furthermore, these parents may feel ongoing pressure to search for a cause for their child's condition when either there is no clear aetiology or a lack of available technology to test a plausible diagnosis [47]. For example, the CDKL5 disorder is a genetic condition causing severe neuro-developmental impairment and refractory epilepsy from infancy [62]. Unfortunately, in Western Australia (along with many other cities in the Western world), genetic testing to confirm a diagnosis is not currently available. Such issues might negatively impact care-giver health.

Summary and implications

Care-givers of children with ASD are more likely to experience many of the risk factors and less likely to experience the protective factors we identified as contributing to poorer mental health. Interventions to reduce risk factors and increase protective factors could pave the way for improved care-giver health. For example, workshops to train parents to better manage challenging behaviours in their children and earlier diagnosis of ASD (and particularly ASD without ID) would seem likely to improve parental wellbeing. Similarly, helping to expand support networks might reduce care-giver burden and stress leading to improved health. High SES is a protective factor for care-giver health. Hence, increased subsidised supports for those of low SES, such as care-giver respite and home help, might also assist care-givers of children with ASD or ID to maintain their health.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

Authors' contributions	JF	YM	HL
Research concept and design	✓	--	--
Collection and/or assembly of data	✓	--	--
Data analysis and interpretation	✓	--	--
Writing the article	✓	--	--
Critical revision of the article	✓	✓	✓
Final approval of article	✓	✓	✓
Statistical analysis	--	--	--

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